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ALZHEIMER'S DISEASE

REPORT

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SUBCOMMITTEE ON
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December 17, 1984

LETTER OF TRANSMITTAL

Honorable Don Fuqua, Chairman
Committee on Science and Technology
U.S. House of Representatives
Washington, D.C. 20515

Dear Mr. Chairman:

I am pleased to submit the report of the Subcommittee on Investigations and Oversight on Alzheimer's disease. The report is based largely on hearings held in Johnson City, Tennessee on August 30 and in Washington, D.C. on September 19 and 20, 1984. This report summarizes the major conclusions of scientists who testified at the hearings. Some of the research results are promising, but Alzheimer's disease will continue to present a major problem for the elderly, their children, and society in general.

Alzheimer's disease, an organic brain disorder, is associated with a progressive degeneration of mental function. The number of victims is relatively large and increasing. The disease, referred to by a leading biologist as "the disease of the century," affects approximately two million American adults, including some 10 percent of those over the age of 65. Presently, there is no known cause or cure. The report outlines the current knowledge and the future research needs.

The report also addresses a very critical issue associated with Alzheimer's disease, which is how to pay for the long term care. About two-thirds of the victims are cared for by their families. Some families pay up to $50,000 for care and treatment of patients and nationwide the cost is approximately $20 to $30 billion a year. Additional economic and financial research and study are needed to explore the various options, the report concludes. The major value of this report is not in resolving the issues but in providing a sound background necessary to understand the scope of the issues involved and to suggest various avenues of action that are available.

I would like to express my appreciation to Dr. Luz Froehlich, a Legis Fellow working with the Subcommittee, for her significant contributions both in compiling background information and in writing this report.

Mr. Chairman, this report adds to the existing body of material resulting from the three days of hearings. I commend it to you and to other Members of the Committee.

Sincerely,

Albert Gore, Jr.

Albert Gore, Jr., Chairman
Subcommittee on Investigations
and Oversight

FOREWORD

The Pulitzer-prize-winning biology author, Dr. Lewis Thomas, also renowned as an educator and researcher, agrees with the balanced approaches to health problems, rather than with those Government officials and biomedical lobbyists who press for attention to and support of individual diseases. However, Dr. Thomas makes one exception: He advocates special consideration and priority for one particular disease. He considers it not just a disease of the month but the "disease of the century'. This is Alzheimer's disease, a progressive, debilitating and eventually fatal affliction that affects about two million American adults. It is most common among the elderly, and its incidence increases rapidly with age. "It is the worst of all diseases,'' says Dr. Thomas, "not just for what it does to the victim but for its devastating effect on their families and friends. It begins with the loss of learned skills...and progresses inexorably with the shutting of the mind....Patients go on and on, living, essentially brainless but otherwise healthy, into advanced age...." [1]

Congressman Claude Pepper, who epitomizes national interest in the care of the elderly, said: "Nowhere in our society are individuals left so unassisted and so exposed to the demands of a catastrophic illness as are the victims of Alzheimer's disease." Congressman Pepper recalled the words of an Arizona man, the husband of an Alzheimer victim, who wrote him: "I find it strange that if my wife had a disease from which she could recover, or was ill with something like cancer where she could be placed in a hospice, she could at least be helped a little bit for a few months; but we are told, with this disease, there is no aid available."[2]

Because of deficiencies in the present U.S. health care delivery system, about 90 percent of the costs of caring for Alzheimer's disease patients are borne by their families. Nursing homes, which generally are not equipped or have the trained personnel to care for Alzheimer victims, often refuse to admit these patients, provide impersonal care or will admit them only if their families offer to pay the full costs of nursing home care which can run to $50,000 a year. The family, if the victim has one, eventually finds itself unable to cope--and drained emotionally, physically and financially.

The Investigations and Oversight Subcommittee of the House Science and Technology Committee, under the chairmanship of Representative Albert Gore, Jr., of Tennessee, conducted three days of hearings on Alzheimer's disease in 1984. The first was held in Johnson City, Tennessee, on August 30, during which caregivers, mostly, gave testimony. On September 19 and 20 witnesses testified on the research into the causes, mechanisms of and cures and treatment for Alzheimer's disease. Research funding needs also were explored as were options in health care funding.

This report describes the disease and its clinical and behavioral aspects including changes in the brain; its incidence; estimated costs for care; the experiences of caregivers; research findings and future research needs; current financing and its problems; and options for alternative care and financing. It is to be hoped that this report will lead to a better understanding of the

scope of this enormously important problem and generate support for legislation addressing it.

"Death has thrust his sword into one who is wide awake."

Dag Hammarskjold, in "Markings"

"That is what dementia does. Death thrusts his sword into one--into millions--who are wide awake."

Paraphrased by Dr. Donna Cohen

RECOMMENDATIONS

1. There is need for increased funding for research on the cause or causes, pathogenesis, diagnosis, treatment, and prevention of Alzheimer's disease and related disorders. Research should be at both the basic and clinical level. Investigations should also be conducted on the various family support systems and other non-institutional community services to determine those that are most cost-effective and of most benefit to the well-being of the patient and the caregiver. While the traditional investigator-initiated, discrete, research projects are encouraged, there is need for coordination of a multi-disciplinary approach, particularly those that involve clinical studies and social services. This can perhaps be best accomplished under the rubric of regional centers of excellence which already have, in existence, a) a central facility for diagnosis, evaluation, and counseling of patients with Alzheimer's disease and related disorders; b) an organization and management of patients with such disorders which emphasize home care and avoids institutionalization as long as possible; c) demonstrated commitments from state public health and social services agencies, and, when necessary, nursing homes.

2. There is need for coordination and sharing of research resources and results among scientists involved in Alzheimer's disease research. While the Huntington's disease model described previously may possibly be emulated, the vast number of Alzheimer's disease cases may require a modification of that model. Further studies and hearings are warranted to explore the best modes of achieving coordination.

3. Additional research of the Medicare/Medicaid system should be conducted and alternatives to financing examined. These alternatives could include social services, keeping in mind that Alzheimer's victims are in less need of acute care than of long-term, custodial care.

4. Further hearings should be held to explore how families as well as family physicians can be educated as to the need for autopsies on the elderly, both those with and without Alzheimer's disease.

5. More hearings should be held on how volunteer organizations can best interact with government and on their future needs to pursue, expand and coordinate their efforts to provide support and disseminate relevant information in a timely manner to families of Alzheimer victims.

6. Additional hearings should be held to consider incentives for medical schools to add Geriatrics to the curriculum and to teach this as a distinct discipline to medical students.

ALZHEIMER'S DISEASE -- OVERVIEW

CLINICAL AND BEHAVIORAL ASPECTS

Alzheimer's disease is a disorder of the brain characterized by a decline in memory and other aspects of cognitive function including awareness of objects or thoughts of perception. It occurs in middle or late life, is more common among the elderly, slowly progresses over periods of from five to 20 years, and results in severe impairment of intellectual ability. This decline in memory and mental function is referred to as dementia. At present there is no known cause and no known cure.

The disease was first described in 1907 by Alois Alzheimer, a German neurologist, psychiatrist and neuropathologist. He recognized the symptoms as fitting into a pattern which was clearly other than just another form of madness, and he described the gross and microscopic findings which he found in the brain at the autopsy of a 51-year-old demented patient. His description of the clinical findings as well as the structural changes in the brain still constitute the basic features of the disease that bears his name.

The early symptoms of the disease may be so subtle as to escape the notice of even the most attentive family member or associate. By virtue of the illness, the patient is often an unreliable witness. Most often the first symptoms are impaired memory and easy distractibility, difficulty in solving simple problems, and failure to respond to the environment with customary speed and accuracy. The patient often turns to schemes and reminders to help his memory in order to function. He draws upon others to serve as surrogate memory. When interviewed by the physician, the patient frequently turns to the spouse or others to supply the details of the history. As the patient becomes aware of the loss of mental efficiency, depression sets in. The depression in turn takes its toll on mental function.

The memory loss is most obvious as it relates to recently acquired information and experiences, but careful examination shows that this impairment involves all aspects of memory to a varying degree.

In the beginning of the illness the physical examination including a detailed examination of other brain functions is usually normal. Thus, patients are of sound body but have serious impairment of intellectual function. Some personality changes may be present throughout the illness, but the most frequent pattern is depression, leading eventually to extreme apathy and withdrawal. Some patients may experience episodes of violent behavior.

At this time the physician must be certain that there are no systemic diseases or other organic or psychogenic brain disorders which may account for the symptoms. For example, depression in elderly patients is common, and is most often correctable with appropriate management. Many older patients take medications for such illnesses as hypertension or diabetes, and some of these medications sometimes cause symptoms mimicking dementia. Such medications should be discontinued temporarily and the patient observed without them before a final impression is formed.

Standard laboratory tests of early Alzheimer patients are normal and, indeed, the diagnosis is made chiefly by exclusion. The CAT scan is most useful in excluding other causes of dementia some of which may be curable. However, in the later stages of Alzheimer's disease a CAT scan may show signs of brain atrophy.

As the disease progresses so does the memory loss and the patient begins to lose other features of brain function. The ability to speak may be preserved, often with a remarkable retention of vocabulary (indeed, a spouse said that her husband, while significantly impaired in other aspects, still retained the ability to do crosssord puzzles). The speech is often empty of ideas, the patient loses the ability to use language effectively, and frequently will have difficulty with geographic orientation, often losing his way in the home or immediate neighborhood. As the patient deteriorates through the ensuing years, there may occur disorders of gait, incontinence, seizures, and eventually complete helplessness.[3]

WHAT HAPPENS TO THE BRAIN IN ALZHEIMER'S DISEASE?

Alzheimer first described the classic neurofibrillary tangles and neuritic plaques seen microscopically in the brain that have become the hallmarks of the disease. Neurofibrillary tangles are nerve cells that contain an abundance of abnormal fibers called paired helical filaments which are highly insoluble. Neuritic plaques, primarily seen in the cerebral cortex, have a central core of a complex protein material called amyloid, surrounded by degenerating nerve endings. While these abnormal structures may also be seen in brains of elderly, non-Alzheimer's disease patients, they are found in abundance in Alzheimer brains.

Until relatively recently Alzheimer's disease was thought to be a generalized pathology of the brain. A major biochemical breakthrough was made in 1976 by Dr. Peter Davies, now of Albert Einstein College of Medicine, when he showed that there is a major deficit in the ability of the Alzheimer brain to synthesize acetylcholine, an important neurotransmitter that permits nerve cells to communicate with one another. Adequate production and release of acetylcholine is extremely important for such functions as memory of recent events, learning new skills, and orientation. Dr. Davies discovered a significant and progressive decrease in the enzyme choline acetyltransferase (ChAT), a key ingredient in the synthesis of acetylcholine.[4,5] Following this exciting discovery, Dr. Donald Price and co-workers of Johns Hopkins University found that in Alzheimer's disease brains there was destruction of a specific group of nerve cells, located in the nucleus basalis, in the deep subcortical area of the forebrain.[6,7] These cells produce acetylcholine, and when acetylcholine is liberated in the brain cortex, the cortex becomes stimulated. For the first time it was thus pointed out that Alzheimer's disease did not start out as a diffuse involvement of the brain as was originally thought, but that specific groups of cells were affected, giving rise to a set of symptoms (primarily memory loss) in much the same way as for example in Parkinson's disease, in which another group of cells is affected, causing another set of symptoms. While the so-called cholinergic system (the system applies to those nerve fibers which liberate acetylcholine at a synapse when a nerve impulse passes) is not the only system affected in the long run, it is the one that is most consistently and most severely involved. Thus, as understanding of the disease developed, symptoms could be correlated with biochemical defects and structural changes in specific areas of the brain. As a result of these breakthroughs, interest in neuroscience research has grown. Initiatives by federal funding agencies, accompanied by increased research, have led to exciting new findings which are described below.

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WHO ARE AFFECTED? ESTIMATED COSTS. WHY IS IT A GROWING PROBLEM IN THIS SOCIETY?

Accurate estimates of the prevalence of Alzheimer's disease are difficult because at the present time, clinical diagnosis is usually arrived at by exclusion, and the most accurate diagnosis can be made only by autopsy. At autopsy about 20 percent of cases are found to have been misdiagnosed. In the past, medical students were taught that Alzheimer's disease is a rare condition. It is now recognized that Alzheimer's disease is a fairly common condition and affects from five to 15 percent of the population over the age of 65. The condition is age-related, that is, the incidence becomes increasingly common with advanced age; on the average one out of five persons 85 years or older has Alzheimer's disease. It is thus estimated that two million Americans have Alzheimer's disease.

Why is Alzheimer's disease a growing problem in American society? Because of advances in medicine and in other aspects of science and technology in the past several decades Americans are living longer. On July 1, 1984, the U.S. reached a milestone: for the first time there are more Americans over 65 years of age than there are American teenagers.[8] Current projections indicate that in the year 2030 there will be 43 million Americans 65 years old or over, nearly double the number today. Thus, if nothing is found to control Alzheimer's disease, we should expect from four to eight million patients with this terrible affliction at that time.

Present costs for caring for Alzheimer's victims run from $17,000 to $50,000 per patient per year.[2] Most of that cost is borne by family members. Federal coverage under Medicare is grossly inadequate. Dr. Robert Butler, former Director of the Institute of Aging, has said that Medicare was designed for people in their 40's and 50's for diseases requiring acute care, and not for people 65 or older who generally need long term custodial care.[9] Private assistance through supplemental and other health insurance policies is almost non-existent for Alzheimer patients. Of all the public programs only Medicaid provides significant assistance--paying $6.5 billion a year for the nursing home care of Alzheimer's patients. But even that assistance is conditioned on the impoverishment of the family (a hardly dignified solution), the availability of nursing home beds, and willingness of the nursing home to keep these patients, for Medicaid pays only part of the costs. About two-thirds of these patients are cared for at home. As the caregiver, usually the spouse or an adult daughter, delivers 24-hour care (indeed, many have referred to caregiving in this disease as "a 36-hour day"), day after day, year after year, physical, emotional, and financial problems take their toll until the caretaker too may become a patient.

THE CAREGIVERS; PROBLEMS OF COPING

"It is a funeral that never ends."10

"When I look back now at the time the doctor came to me and said, 'Thank God she doesn't have a brain tumor,' I have often thought how lucky we would have been if it had been that, because perhaps she could have been cured at that time."11

"Caring for an Alzheimer's disease patient is like caring for a two-year-old child. The big difference is that the patient never improves; he only gets worse. A caretaker must dress, feed, bathe the patient, continually check on body functions 24 hours each day, year after year, for maybe 20 years. Patients must constantly be watched so that they don't fall or hurt themselves or swallow something they shouldn't. The caregiver has to be cautious not to become upset over the constant mistakes the patient makes. When he goes to the bathroom on your favorite piece of furniture, it's hard to stay calm. Many patients' sleep is interrupted from time to time (and consequently) a caregiver finds himself going 24 hours a day without proper sleep. We must also make the inevitable trips to the bathroom during the night." These are the words of the son of an Alzheimer's disease victim, describing the plight of his mother, the primary caregiver, whom he helps from time to time. He adds further: "Although (my dad) is a veteran, the V.A. Hospital offers little encouragement for long term care. We could spend down what we have saved for a lifetime and leave Mom with no buffer as she gets older. People go to great lengths to beat the system as it is now drawn, so they will qualify for Medicare insurance. It sometimes becomes almost a blessing if he (the patient) has a stroke or some other illness that qualifies him for assistance.... Those of us who work to keep our patients healthy are further penalized.

This is a definite 'Catch 22' situation."[12]

These expressions of frustration, grief, and desperation pervaded the testimonies of the caregivers and their immediate families. One witness, a nurse whose mother had been caring for over 30 years for her ailing father with Alzheimer's disease, lost her composure twice while describing her mother's caring and her own participation in providing support and professional knowledge.

Another caregiver's husband was an electrical engineer until 10 years ago, when his symptoms became pronounced enough so that his company retired him on disability. When the diagnosis was first made (it was called pre-senile dementia then; not until a year later was the term Alzheimer's disease used) she and her children were told by the doctors that the condition would eventually be fatal. She was told to take her husband home and wait for him to die. She was given no instructions on how to take care of him. The family was not prepared emotionally and financially for this drastic change in their lives. She went to work. Her growing concern for her husband being left unattended in the house and her love for him made her quit work so that she could devote all her time to him. She described how, when she had to go shopping for food, the would take him with her, lock him in the car, dash in and out of the supermarket hoping all the time he would not do anything to hurt himself. During one of these episodes, he in fact managed to release the car's

emergency brake and she found the car rolling in the parking lot. The husband now has reached a stage where he has completely lost his ability to speak and all control of his body functions. She sometimes would catch herself talking about her husband in the past tense as if he were already dead. "I am a widow with a husband. I am a social leper. Our children no longer have a father. The body that was their father still exists, but the loving, caring father is no longer there."[13]

There was not a dry eye in the audience during the testimony of these caregivers.

These experiences recounted by these witnesses belie the common myth that the American family has abandoned its elderly. About two-thirds of people with this disease are currently being taken care of by their families, according to the studies of Dr. Peter Rabins,[14] Dr. Carl Eisdorfer,[15] and others. Said Dr. Carl Eisdorfer, "If you have Alzheimer's disease and you haven't got a family, get one."[16] The role of caregiver is enormously taxing and relentless in its demands. Relationships that have developed, often over a lifetime, are suddenly changed and that can put a severe strain on families. It is thus not surprising that when families are asked how they are doing, they tell the doctor that they are discouraged, they get angry, they feel embarrassed and guilty that they have yelled at the patient.[14]

The social fabric of the family also changes. The caregivers are physically exhausted at the end of the day and therefore are too tired to make social contact; at the same time, the well persons lose many of their social contacts or most of the supports they have had earlier.[14] Depression is quite common among the caregivers. In a study completed at Montefiore Hospital in New York and recently reported to the Gerontologic Society, it was found that of the primary caregivers living at home with the patient, more than half showed significant symptoms of depression after about one and one-half years.[15] In many instances the caregiving spouse, if he or she too is elderly, may also have a physical, chronic illness, compounding the problem. Thus in the words of a caregiver, "In Alzheimer's disease, you have two victims: the patient and the caregiver."[17]

It is obvious then that the caregivers must be given some respite, some relief, from this burden of caring.[18] Among the most important are self-help groups. Family self-help groups composed of relatives caring for older adults with Alzheimer's disease or other related disorders have recently emerged throughout the U.S. The heart of the movement is the small local community group which meets regularly in a public library, church, school, nursing home, hospital, or home. These people share experiences and, by sharing, they help each other cope with the impact of the illness on his or her own family. The sheer existence of the group provides the needed emotional support to the caregivers who live with the stresses and strains of 24 hour care.[18] The Alzheimer's Disease and Related Disorders Association (ADRDA) is a national organization established in 1980, composed of family support groups from all over the nation. Most of the Chapter leaders have a loved one with Alzheimer's disease.[19]

Day care centers, if they are available, are a very important resource for some families. These facilities can give respite to the caregiver for a few hours, a day, or a weekend. Unfortunately, there are relatively few such centers

available. Proximity and the availability of transportation, as well as the ability of the patient to be transported are obvious considerations. There may even be need for units, such as in a certain section of a nursing home, where the patient could stay for one or two weeks to give the family a break from care.

For patients in the early stage of their illness where no professional care is needed, a neighbor or some non-professional could come in a few hours a day.[18] It was suggested by Dr. Peter Rabin that studies should be conducted to determine whether the relief services mentioned above actually do make a difference. If they do, it is his belief that nursing home placement could be delayed for a significant length of time, which not only would mean tremendous savings in cost, but may be better for the emotional well being of the patient. Finally, educating the family through informational material (the ADRDA is performing a very commendable job in this respect) is extremely helpful. Further, the family physician plays an important role. He or she should carefully discuss with the family what symptoms and behaviors to expect, how to cope with them and how to maximize the strengths and capabilities the patient still has. These can go a long way in making it easier for both patient and caregiver to cope.[14] It is sad to know that up to 75 percent of families have stated that they have had little or no instructions from their family physicians on what to do or how to care for the patient at home.[19]

RESEARCH FINDINGS

BIOCHEMICAL AND STRUCTURAL CHANGES

Less than ten years ago, all but a few experts in the scientific and medical fields believed that Alzheimer's disease was a rare brain disorder typically occurring in people in their early 50's. It was also believed that forgetfulness and confusion and other so-called senile-like symptoms were a normal part of aging. Very rapidly, within the past few years, after the breakthroughs that were described above, Alzheimer's disease has become recognized as a definite disease entity and not just a natural consequence of aging. Hopefully, therefore, through research, we may be able to prevent it or, failing to do so, to treat it.[20]

The fact that Alzheimer's disease has now been shown to be a focal, not a generalized brain disorder, starting in one area of the brain and then later affecting other areas, permits researchers to know where to look so that intervention may be possible. The biochemical discovery described above on neurotransmitters has given us a better understanding of what is happening in the brain in Alzheimer's disease, and intelligent questions can now be asked and explored.[21]

An important finding has been that the neurofibrillary tangles in the Alzheimer brain are made up of an unusually insoluble protein. Further, it is known that the nerve cells of healthy old persons show continued regrowth of dendrites (the branch-like extensions between nerve cells through which messages are received), but in Alzheimer's disease, this regrowth apparently does not occur.[20] We have mentioned above the marked loss or deficiency of acetylcholine and its synthesizing enzyme. A new research device, the Positron Emission Tomography (PET) scanner is now in use as an important research tool in 10 institutions in the country. With this new technology, which is non-invasive, we can "watch the brain think and we can watch it work." The patient can be asked to do tasks after being given radio-labelled glucose. For example, the patient is asked to think about moving a finger, and the part of the brain that controls that process lights up on the screen. As this part of the brain begins to increase its consumption of glucose the person is then asked to move that finger, and other parts of the brain concerned with that action become incorporated and again show on the screen. In Alzheimer's disease using the PET scanner has shown that brain metabolism is reduced with advancing disease as evidenced by the brain using less glucose, a substance necessary for the production of acetylcholine.[21]

Studies of structural changes in certain regions of the brain have been recently extended by the works of Hyman, Damacio, and others at the University of Iowa.[22] They have shown that in Alzheimer's disease, certain groups of cells in the so-called subiculum and the entorhinal cortex, exhibit pathology. These cells are precisely those that interconnect the hippocampus (a part of the brain involved in memory) with certain areas of the brain that are crucial to memory, such as the basal forebrain, thalamus, and hypothalamus. This isolation of the hippocampus from these regions and the cerebral cortex results in memory disorders as well as some processes of recognition, according to the authors. These findings complement those described by Dr. Price and co-workers from Johns Hopkins.

Another recent discovery that has generated excitement was that reported by Dr. Charles Marotta from Harvard Medical School and McLean Hospital.[23] Heretofore, it had always been assumed that DNA (the basic blueprint of life) and RNA (essentially a "soft copy" of DNA) were too fragile to survive the postmortem interval prior to freezing the brain. Dr. Marotta has shown, however, that, in a number of cases, frozen and stored brains can be used to prepare RNA that retains some of its functional ability. Having verified that human postmortem RNA remains sufficiently functional for experimentation, he applied these methods to donated, frozen brains of Alzheimer's disease victims, and observed that the most demented brain areas had low amounts of extractable RNA, thereby suggesting decreased synthesis of the functional proteins in the brain cells. One of the contributing factors was the excessively high activity of the brain enzyme that destroys RNA. Dr. Marotta said that this finding has been confirmed to some extent by French scientists who, using the PET scanning technique, demonstrated that the brains of living, severely demented patents produce only about half the amount of protein as that produced in the brains of non-demented individuals of the same age. The most useful outcome of these research efforts, according to Dr. Marotta is that, since human brain polynucleotides have been shown to have survived the postmortem state, they can be used for recombinant DNA experiments. This opens up a whole new avenue of exploration which molecular biologists had said could not be done.[24]

GENETICS

It is generally believed that familial Alzheimer's occurs in 15 percent of all Alzheimer's disease patients. The investigations of Dr. Leonard Heston, University of Minnesota,[25] show that, unlike many other dementing diseases which display a bell-shaped curve in age distribution, Alzheimer's disease increases in frequency with advancing age. Thus, below the age of 65, the incidence is about 5 percent or less; however, for the age group of 80 and beyond, the incidence rises to some 20 percent. He also found that, the earlier the onset of the disease, the shorter is the average survival and the greater is the severity of the disease.

Dr. Heston noted that people who are predisposed to familial Alzheimer's disease get the disease at earlier ages. In these instances, the so-called proband, or the person through whom the family is located, tends to have a more severe case and there is likelihood that another, older, relative will also have the disease. Conversely, if the disease is first noted in an old person and there is no other person in the family affected, the likelihood of a familial tendency in that family is small. Dr. Heston also showed an association between Alzheimer's disease and cancers of the lymphoma type, reminiscent of a similar association between Down's syndrome and leukemia. It is these families, he believes, that are suited for investigations using recombinant DNA technology and various types of genetic and biochemical studies.

He reaffirmed the now well-known finding of the close relationship between Down's syndrome and Alzheimer's disease. If a Down's syndrome patient survives beyond 40 years of age, he will, in all probability, develop Alzheimer's disease with the classic pathologic brain changes. Another interesting finding, offered by Dr. Peter Davies in an earlier testimony,[5] is that, when the pregnancy records of women with Alzheimer's disease are examined, they reveal that those mothers have a much higher frequency of having had Down's syndrome babies than could be explained by chance alone.

It is reassuring that the truly high-risk families are small in number (3-4 percent of families studied), and here, the age of onset is generally in the 40s. These families need to go to a genetic counselor. In such families, by about age 70, the total risk runs as high as 40 percent. In the Minnesota studies, only about one-third of all of the families investigated had a second case at all; that is, in two-thirds of families studied in which one had Alzheimer's disease, there was no evidence of a familial tendency.[25]

POSSIBLE VIRAL ETIOLOGY

The possibility that Alzheimer's disease may be caused by a slow virus has intrigued many investigators. This hypothesis is based on the many similarities between Alzheimer's disease and those dementing diseases, kuru and Creutzfeldt-Jacob disease, that have been proven to be caused by a slow virus. According to Dr. Manuelides of Yale University,[26] similarities include dementia, brain wave changes, and certain brain Pathologic changes, including senile plaques, "spongy" changes, and neurofibrillary tangles. In some families, both Alzheimer's disease and virus dementias may occur. In a few instances, within the same patient, the changes of virus dementia and Alzheimer's disease co-exist. Despite these similarities, no one has yet been able to transmit Alzheimer's disease to laboratory animals. The possible explanation is that, since transmission experiments are all done from autopsy material, only the end stage of the disease is being examined where viable viruses are no longer present and only the destructive effects of the virus remains, according to Dr. Manuelides. Thus, if diagnoses can be made early, before overt symptoms, recovery of the virus may be possible if, in fact, the cause is viral. Several laboratories around the country are vigorously pursuing this line of investigation.[26]

Recent research suggests a similarity between the amyloid deposits in the brain tissue of Alzheimer victims and virus-like particles, so-called "prion," found in a dementing disease in sheep.

OTHER RESEARCH FINDINGS

Another search for cause, though controversial, implicates an environmental toxin such as aluminum which could affect brain cell metabolism. Dr. Khachaturian, National Institute on Aging,[27] theorises that there is a defect in calcium regulation within the nerve cell in Alzheimer's disease based on two observations. First, there is a decreased amount of the neurotransmitter, acetylcholine, that is released from brain cells of some Alzheimer's victims. The release of the transmitter is dependent on calcium being present in the cell. Second, the brain cell's ability to utilize glucose, which depends on the amount of calcium, is defective in some Alzheimer's victims.

Transplantation of brain tissue to lesioned animals are being performed in some laboratories, including that of Dr. Davis at Mt. Sinai School of Medicine and the results appear promising.[28] However, investigators caution that any thought of applying this technique on humans is still quite remote.

A recent study conducted at Dartmouth Medical School concerned the infusion of a drug, bethanechol chloride, directly and continously to the brain by way of a pump implanted in the patient's abdomen.[29] The technique was used on four Alzheimer's disease patients for up to one and one-half years. The authors reported improvement on three of the four. However, other scientists have mixed reactions about this procedure.[30] The authors themselves cautioned against premature high expectations from this procedure since the study was a preliminary feasibility trial. Still, the preliminary results are encouraging. Bethanechol chloride is a drug believed to mimic the action of acetylcholine.

DIAGNOSIS, TREATMENT, AND CARE

BETTER CLINICAL DIAGNOSIS AND MANAGEMENT

At the clinical level, there is increasing recognition of the absolute necessity to carry out a thorough differential diagnosis and to rule out potentially treatable causes of dementia before concluding that a person has Alzheimer's disease. Too often, multiple diseases in the elderly obscure the symptoms of Alzheimer's disease, or speed the progress of the disease.[20]

In the July 1984 edition of the journal Neurology an article appeared entitled "Clinical Diagnosis of Alzheimer's Disease". This paper was prepared by a work group of scientists and physicians under the auspices of the Department of Health and Human Services Task Force on Alzheimer's Disease. It defines specific criteria for clinical diagnosis of the disease and specifies three different diagnosis categories: probable, possible and definite Alzheimer's disease, as well as criteria for classification of the disease for research purposes. Aspects of medical history, clinical examination, neuropsychological testing and laboratory assessments that can contribute to a diagnosis of probable Alzheimer's disease are described in the article. These publications are being widely disseminated to health professionals and it is believed they will aid individual physicians and improve the accuracy of diagnosis.[21]

Additionally, the Task Force has prepared a brochure called "Alzheimer's Disease, A Scientific Guide to Help Practitioners." This brochure, written in terms that all physicians at every level of practice can understand, is now being spread nationwide.[21]

There is much work going on which attempts to define and understand better the manifestations of Alzheimer's disease; the precise nature of the cognitive, linguistic, and sensorimotor deficits associated with this disease; the variations in the course of the disease; and the impact on the families of affected persons. Two important goals are to learn enough about the disease to develop more sensitive and reliable diagnostic tests and to improve patient care.[20]

At the level of treatment, efforts are under way in a number of research settings to test the effectiveness of various drugs on brain function. To date, most of these studies have attempted to increase or maintain the levels of acetylcholine in the brain and to test other substances for their ability to improve the responsivity of the target nerve cells to the action of acetylcholine. These efforts are still at the experimental stage; it is too soon to state with andy confidence whether they might be effective.[20,28]

But even without an effective drug therapy for Alzheimer's disease, much can be done to help patients and their families manage and live with this disease. The most practical aids are carefully structured, regular daily living schedules in familiar settings; good medical care; selective use of home support services; and information and social support for the family members. With the help of such groups as the ADRDA, most families can get along for long periods of time, but at what is often a heavy emotional and physical price for everyone. Arrangements for respite for the family members through temporary

substitute care for the affected person are most important.[20] Even if Alzheimer's disease is present, it is important to help the affected person remain independent for as long as possible.

"The latest evidence supports the idea that the patient's family, where available is the foundation of care," asserts Dr. Eisdorfer, of the Montefiore Medical Center.

"Families are the most significant, unpaid health and social resource in the United States for Alzheimer's patients. But the family is not getting the help it needs. They need information as to the nature of the illness, about genetic concerns, about resources in the community, the existence of family health groups, legal and financial advice which is a very key role in the management issue. They need to understand on-going care and physical changes in the home which could help manage the patient.

Most families care for their own and go to extraordinary lengths to provide care. For most individuals, the need to institutionalize a spouse or a parent evokes considerable upset and guilt and, as a rule, reflects an act of desperation."[15]

TREATING THE SYMPTOMS

As has been stated, there is, as yet, no known cure for Alzheimer's disease. Since memory loss is one of the earliest and most striking symptoms, most clinical investigators tend to focus treatment modalities on the improvement of memory. But when one talks to families, according to a psychiatrist,[31] memory is not usually the biggest problem. The most problematic symptoms, in terms of management, are incontinence, wandering, and sleep problems. Other problems relate to thinking and behavior, perceptual problems, trouble dressing (apraxia), and communication problems (patient has trouble expressing himself).

To deal with these problems, an intervention should be structured that will allow the patient to do what he or she still can do. Instructions should be given only one at a time. Because impairment of judgment can be one of the earliest symptoms, the caregiver should be prepared to take over some of these responsibilities. Patients tend to be frustrated easily over minor things; thus, the family should take out those irritants. The principles of management are: 1) Know the specific problems and know the patient's strengths; maximize these strengths; 2) Provide a stable, consistent environment. The environment should be stimulating but not overly so; 3) Expect that most of the changes must have to be made in the environment, not on the patient; 4) Try to maintain the dignity of the sick person; 5) Avoid drugs whenever possible.[31]

RESPITE CENTERS

As was mentioned previously, the primary caregiver needs respite from around-the-clock caring for the Alzheimer victim. Day care centers offer a solution to many, by allowing respite for a few hours, a day, or a weekend. One witness, who is executive director of a respite center, described why the center she directs has been highly successful.[17] The center is unique in that the staff consists almost entirely of volunteers who go out of their way to donate their services to the center, which is the only one servicing Memphis and Shelby County, Tennessee. Each volunteer cares for only one patient for the day. There are planned activities, designed to meet each patient's individual needs and capabilities. Each activity is intended to keep the "participants" (as they refer to the patients) content, aware of their environment, occupied, and aware that they are cared for and loved. Since the building and maintenance were donated, as are most of the services, the charge per patient is minimal ($8.00/day, plus $2.50 for lunch).

The experiences shared by those in charge of other day care centers[39] generally followed a similar pattern as that described by the witness: stimulating, pleasurable, non-frustrating types of activities are given to the patients by a familiar set of people who show that they care. The staff:patient ratio runs from 1:1 to 1:6, but averages about 1:4. The charges per patient vary from $10 to $150 per day, averaging about $30 to $50 per day. To keep the costs down, volunteers are needed. Acording to Dr. Pfeiffer, Director of the Suncoast Gerontology Center, a University-based, community-oriented research based center in Florida, patients in the early stage of the disease generally do not require a day care center; on the other extreme, those that are far advanced probably would not do well in a day care center and might be more properly placed in a nursing home. He indicates that the criteria for admission to a nursing home are: 1) If the patient can no longer assist in his daily activities; 2) If the paid caregivers "quit" or give up; 3) When the patient can no longer relate to or recognize the spouse; and 4) When the principal caregiver can no longer give the proper care.[39]

POLICY ISSUES

GOVERNMENT INVESTMENT IN RESEARCH

The three agencies of the Public Health Service with a major investment in the support of biomedical and behavioral research on Alzheimer's disease are the National Institute on Aging, the National Institute of Neurological, Communicative Disorders and Stroke (both at the National Institutes of Health), and the National Institute of Mental Health, of the Alcohol, Drug Abuse and Mental Health Administration. Among these three, the total investment in Alzheimer's disease research is close to $40 million. This is about a ten-fold increase from the 1976 budget of $4 million.[32] Most of this money goes for the support of the traditional research projects. The reader is referred to the Report of the Secretary's Task Force on Alzheimer's Disease which contains a listing of all active grants (as of October 1983) funded by these institutes relating to Alzheimer's disease.[33]

In FY '84, Congress appropriated $3.5 million for the establishment of five Alzheimer's disease Centers, to be administered by the National Institute on Aging. When the program was announced, 22 applications were received.[20] The five centers that have recently been awarded are at: the Harvard Medical School/Massachusetts General Hospital; the Johns Hopkins Medical Institution; Mt. Sinai School of Medicine in New York; the University of California in San Diego; and the University of Southern California. Each center will provide shared resources for established investigators working on basic, clinical, and behavioral studies of Alzheimer's disease and related disorders. They will also fund new research projects and train scientists and health care providers new to Alzheimer's research.[34]

Included in the Labor HHS Appropriation bill for FY 1985 was a request for $5 million to establish five additional centers to find a cure for Alzheimer's disease and related disorders. The bill was signed in November 1984.[35]

The directors of these funding agencies expressed their gratitude to Congress for their interest and concern for the debilitating diseases. They assured the subcommittee of the collegial and collaborative relationships among scientists and administrators in these institutes. Research grant applications are assigned to as many institutes as appropriate so that each may consider the application for funding.[20,21,36]

THE VETERANS ADMINISTRATION

Dr. John Mather, Assistant Chief Medical Director for Geriatrics and Extended Care for the VA, discussed at a recent conference what the VA is doing for older veterans, including those with Alzheimer's disease.[40] He presented some rather sobering figures. Of the 23 million veterans, four million (17 percent) are over the age of 65. Moreover, the current average age of veterans from World War II is 65. The projections are that, by the year 2000, about 37 percent of all veterans will be over the age of 65. In 1980, 200,000 veterans had dementia, mostly senile dementia of the Alzheimer's type (SDAT); by the year 2000 the number is expected to be 500,000.

In setting their goals for the care of the aging veteran, the VA policy-makers cannot ignore costs but neither can they ignore the quality of life nor the increased life span of the individuals. Because of the shortage of VA beds there is a shift towards increasing use of outpatient facilities and institutional long term care outside of the VA hospitals. The goal is to encourage the patient to function at his own level of independence, a difficult task in SDAT. Within the VA system, the emphasis is on service-connected disability; therefore, SDAT not being service-connected, the veteran with Alzheimer's disease is eligible for a VA hospital bed only on a space-available basis. Thus, the Agency has resorted to contracting out services for these veterans to nursing homes. Of the 24,000 nursing home beds in the United States, 35 percent, according to Dr. Mather, are VA operated. However, another problem is that this type of VA community nursing home program is supported only for six months for each veteran, after which time the patient must be supported by Medicaid. The challenges encountered with this transfer, needless to say, often cause significant problems to the patient and caregiver.

There are 48 geriatric assessment units within the VA system, and it is in these units that the Alzheimer patient is given a comprehensive medical/social assessment. This assessment is conducted in conjunction with the family, to determine the appropriate placement for the patient.

The VA is seeking legislation to permit reimbursement to the family for respite care. This would be a major deviation of VA's entitlements, but the intent is to prevent "burnout" of the family which in the long run would be more cost-effective. The agency is examining many directions for the future such as ways of achieving the maximum level of independence of the patient and increase in research, both biomedical and health services. The total VA budget for research is $155 million, of which only a small fraction goes for Alzheimer's disease research.

Additional future efforts include support of the family, educating them on coping skills; redirecting staff attitudes towards caregivers; and contracting for general home care and for hospice services.

CURRENT FINANCING AND ITS PROBLEMS

Dr. Robert Butler has often said that, although specifically intended for the elderly, the Medicare benefit package was designed as though it were for young people. Preventive services and custodial or long-term care are specifically banned from reimbursement. Thus, as was mentioned earlier, help to the family from Medicare is minimal, is almost non-existent in most private-insurance packages, and the family has to "spend down," or be impoverished before it can turn to Medicaid for assistance. The Medicare or acute-care model is clearly inappropriate in an era dominated by chronic disability.[37]

While Medicaid attempts to address the sociomedical problems of the very poor or those who have become so, the national average for those elderly that qualify for Medicaid is only about 13 percent, according to Dr. Anne Somers of Princeton University. Reimbursement, too, is generally low, such that most of the best physicians and some of the best nursing homes refuse to accept Medicaid patients.[37] Thus it is that most of the financial burden of the care and management of Alzheimer's victims are borne by the family whose members, we have indicated earlier, already suffer considerable emotional, physical, and mental stresses. To allow this state of affairs to continue unremedied is unconscionable.

Dr. Carl Eisdorfer, who testified before the Subcommittee on alternatives to health care financing, gave thoughtful consideration to this important and complex issue and his comments are herewith quoted:[15]

"It has become apparent that Medicare and Medicaid as they now exist, however costly, are not adequate to meet the needs of our aged population and their families. The design of our financing programs are at issue. Because of the way Medicare was structured to only meet the acute care needs of the aged, and the virtual absence of private insurance for long-term care in the United States, Medicaid has become the principal payer for long-term institutional care in the United States. Thus, we pauperize such families in long-term care institutional settings and then provide Medicaid financing, when less expensive home-based alternatives could be made available.

"Initiatives are needed to examine the possible role of catastrophic insurance for Alzheimer's disease. Alternate forms of group coverage may also be possible. Special legislation to allow for the support of spouses through tax relief for caring for patients at home as an alternative to institutionalization should be tried. Since family care is far and away the most cost effective way of helping patients, it should be supported and encouraged.

"Social and personal supports as a component of a health insurance program--or prepaid group plans--should be developed as another approach to helping maintain the Alzheimer patient at home. Since such services can also be preventive in nature and help keep patients out of costly institutions, this is an investment which could lead to important savings as well as an improved quality of life for the family. The role of respite care, in which families caring for patients can have relief for one or two weeks with needed vacations, trained geriatric social workers working as a team with doctors and nurses to help provide care at home, day care centers, sheltered housing and similar

social and environmental supports have all been demonstrated to successfully keep patients out of nursing homes. Eventually, a plan to organize such community and medical services for families will have to be undertaken. This bridging of social services and preventive health care will do much to alleviate the burdens of cost and of caring. It only demands that we take on these initiatives.

"The goal should be to avoid change in current policy that places hardships on families with cognitively impaired relatives, to develop policies that provide alternative ways of strengthening families, and to provide the options families need to cope with their self-imposed burden of caring. Caring and the value of human life are a part of our moral fabric."[15]

Dr. Anne Somers, in a statement prepared for a hearing in July 1984 on home care made the following specific recommendations on policy changes with respect to long term care (LTC):[37]

"1. Broad Policy Changes. Congress should be urged to undertake a thorough review and amendment of the basic Medicare statute to effect the following major changes:

   a. Removal of the ban against 'custodial care' and restatement of the overall Medicare objective to provide 'comprehensive health benefits' to the elderly and seriously disabled, to be provided in 'the most health-and cost-effective setting,' and to include related social services;

   b. Transfer of primary responsibility for long term care for the elderly and seriously disabled from Medicaid to Medicare;

   c. Imposition of annual budgetary limits on the entire Medicare program;

   d. Establishment of some internal limits on expenditures for acute care as opposed to long term care, with possibly no more than half going for acute care after a period of transition;

   e. Provision for non-deterrent patient cost-sharing for both acute and long term care benefits;

   f. Requirement of fixed prices (not necessarily DRGs) on all provider services and goods, to be periodically adjusted, preferably through negotiation;

   g. Provision for basic administrative changes, such as merger of Parts A (hospital benefits) and B (physician services), if necessary to achieve maximum administrative efficiency;

   h. Provision for appropriate local or community administration of long term care benefits to include functional assessment, case management, and a practical definition of physician/case manager relations.

"2. Program specifics. Within the broad new Congressional mandate, committees of experts, responsible to Congress and/or the Administration, should work out the specifics, including:

a. Specific definition of long term care services to be covered and for how long, how and by whom they should be provided, and how paid for;

b. A timetable for gradual transfer of substantial resources from acute to long term care, and how to enforce;

c. Schedules for non-deterrent patient cost-sharing for various benefits;

d. Permissible models for local administration of long term care benefits.

"Clearly, this does not cover all the problems and complexities that would be involved in such a reorientation of the Medicare program. Nevertheless, it indicates the essential direction of change and the importance of an early start so that deliberations will not be hampered by a sense of panic that will inevitably follow if we wait for the predicted crisis in the Medicare Trust Funds to arrive. The time to act is now, while we still have time to think clearly."[37]

THE REPORT OF THE SECRETARY'S TASK FORCE ON ALZHEIMER'S DISEASE

Secretary Heckler established the Health and Human Services (HHS) Departmental Task Force on Alzheimer's Disease, which first met in April 1983 under the chairmanship of Assistant Secretary Edward N. Brandt, Jr., M.D. The mandate to the task force was to produce an in-depth study of the current state of medical knowledge of Alzheimer's disease "and a blueprint that would put the victims, their loved ones, and medical science on the pragmatic and scientific road to progress."

Membership on the Task Force consisted of ten agency and program heads from across the DHHS and the Veterans Administration. Experts throughout the country on Alzheimer's disease contributed to the work groups to make recommendations on what were identified as nine problem areas. The Secretary's Task Force Report was released on September 19, 1984.[33]

The report is clearly a well-prepared scholarly document which lists the state of the science, and details where future research is needed. It is apparent that considerable study and effort have gone into the preparation of this document. It should be required reading for all concerned with Alzheimer's disease. Recommendations for research run the whole spectrum of research on epidemiology, etiology and pathogenesis, diagnosis, clinical course, treatment, the family, and systems of care. Additional recommendations are for more training of investigators and academic leaders in all appropriate disciplines, and for more active and coordinated information dissemination of educational materials both to the practitioner and the family. A final special financing recommendation removes the limitations on (physician) services provided to Alzheimer's victims outside the hospital setting.

While this report is comprehensive, there is an obvious lack of allusion to the current inadequacies of the Medicare/Medicaid system in addressing the long term care of Alzheimer's disease victims. Thus, except for the special financing recommendation referred to above, no new solutions to the current problems of the victims and their families are offered. Regardless of the purported insolvency of Medicare by the early 1990s it would seem that restructuring of what appears to already be an obsolete system, or alternatives in health care financing, could have been recommended.

ADDITIONAL ISSUES IN RESEARCH

Future research directions enumerated by expert witnesses, both research scientists and heads of concerned funding agencies, were basically similar to those listed in the Secretary's Task Force Report and will not be repeated here. However, some concerns were expressed by the scientists who testified which need further exploration or should be addressed.

1. At the hearing, scientists decried the fact that the average length of time for a research grant is three years, which often gives precious little time to come up with meaningful results. While these scientists can apply for a competing renewal of their grant, the process of preparing a good grant application that would stand the scrutiny of peer review takes several weeks, time which could be spent in the laboratory. They praised the NIH peer review process, but they did feel that five-year (regular) research grants should be allowed, particularly in complex projects in which immediate results are not readily attainable.

2. There is a tendency for peer reviewers to give better scores to "safe" research, those that are likely to be productive and based on "reasonable" hypotheses. They are less likely to give good scores to what some would call innovative, or "high-risk" research, or those which do not run along the lines of current scientific thought. One scientist suggested that there be a small pool of money to fund such high risk research.

3. There is a need to educate the public to grant permission for autopsies on their deceased, elderly relatives. There seems to be no incentive to seek autopsies on those who "die of old age." The problem is most acute for non-Alzheimer brains. In a recent letter to the editor of the New York Times, the Chief of Psychiatry at a home for the aged, wrote: "It is ironic, and potentially disastrous, that now that federal funding of research into Alzheimer's disease is making major advances possible, the number of autopsy permissions being granted for aged patients is rapidly declining. Every family with an Alzheimer's patient learns there is--as yet--no effective treatment. Yet when that patient dies, personal repugnance toward an autopsy leads to a refusal to permit one.

   "At the moment of bereavement, this is understandable. Yet unless brain tissue of the aged--both those who had Alzheimer's disease and those who did not--is available to research teams, no amount of funding will produce the information crucial to preventing and curing this horrible disease."[38]

4. There is a need for more coordinated sharing of research resources and results, a so-called "Center Without Walls." Dr. Davies referred to the Huntington's Disease model, in which a coordinator, a health scientist administrator at the NIH, tracked down affected families, gathered scientific results submitted by NIH-funded investigators in that area of research and disseminated information to concerned investigators. In other words, while there already is, allegedly, a sharing of information and a coordination of effort among the program administrators and heads of funding agencies, there should be a similar sharing of resources and research results among investigators on Alzheimer's disease which could perhaps be best accomplished by having a central coordinator.

5. There should be more freedom and flexibility in research, and refrain from targetting research on a specific disease. Mandating studies on a specific disease often frustrates and stifles creativity among research scientists. The structural changes described above which provided a major breakthrough in Alzheimer's disease research were discovered by Dr. Price and co-workers when they were working on Huntington's disease.

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